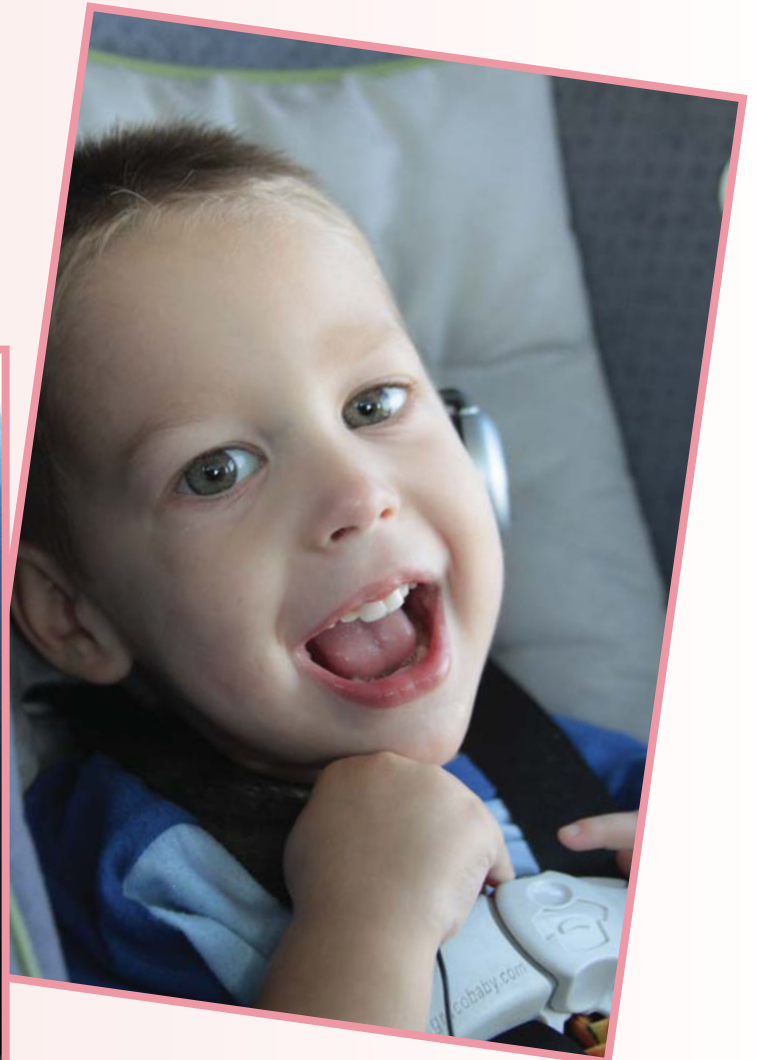


Year at a Glance

2012-13



What is First Steps?

First Steps is Missouri's Early Intervention system for infants and toddlers, birth to age three, who have delayed development or diagnosed conditions that are associated with developmental disabilities. First Steps is a voluntary program which provides families the tools they need to help their child be successful. Families play an integral role in their child's development.

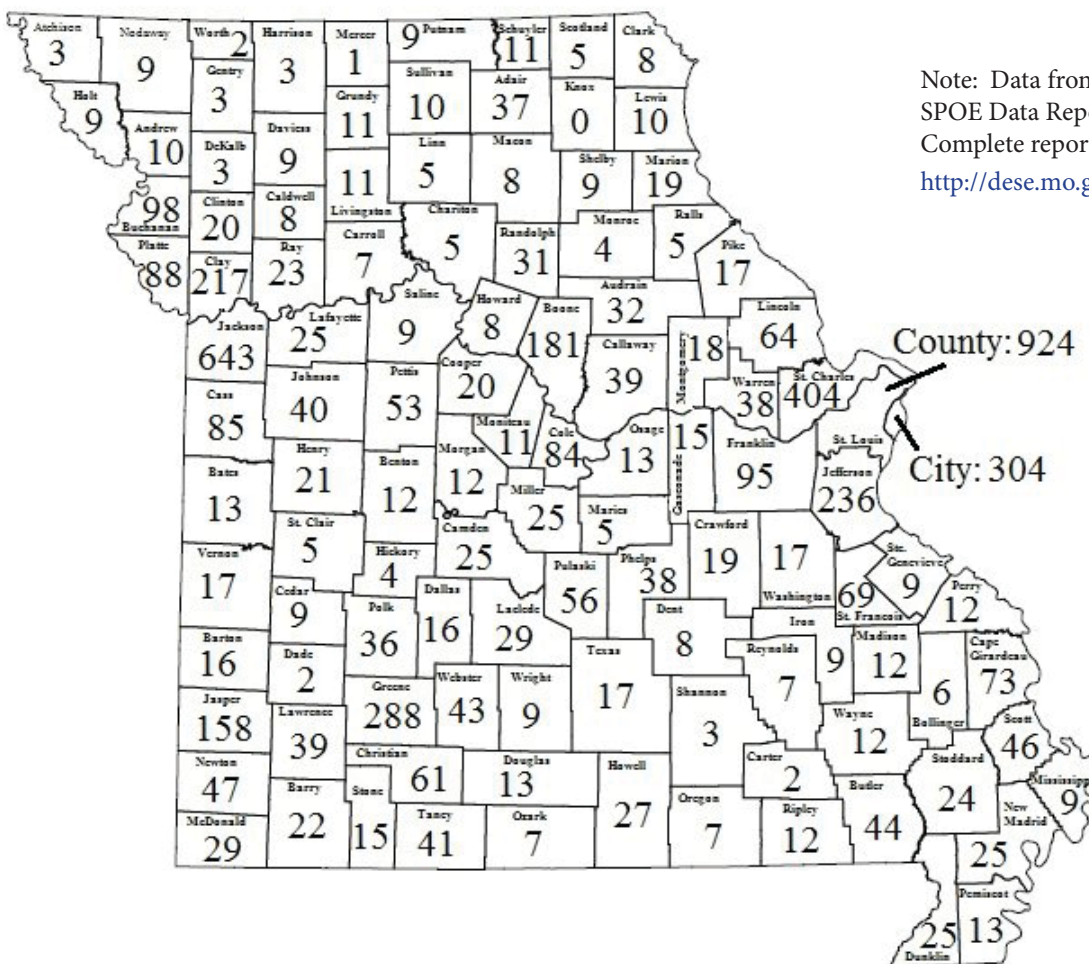
What is a SPOE?

First Steps is operated through contractual agreements in ten regions across the state. The ten regional offices are known as System Points of Entry (SPOEs) and they provide service coordination, intake and eligibility determination, as well as all local administrative activities for the program. Building a strong network among the SPOE and primary referral sources in a community assists in the early identification and referral of children who are potentially eligible for First Steps. Missouri is a geographically diverse state, yet regardless of location within the state, all Missouri children and families receive support from a SPOE in their area.

What is an IFSP?

Children found eligible for First Steps have an Individualized Family Service Plan (IFSP) which reflects a family's concerns, priorities and resources with regard to the development of their infant or toddler. Families participate as partners in the planning, development, implementation and review of their IFSP. The IFSP process is unique to each family. Service coordinators and service providers recognize that families are diverse, and collaborate with family members to ensure the development of meaningful goals and related services that assist the family in improving their child's functioning in everyday routines and activities.

Number of Children Served by First Steps in Each County



Note: Data from First Steps
SPOE Data Report – July 2013.
Complete report available at:
<http://dese.mo.gov/se/fs/data.html>

To Make a Referral to First Steps,

call toll-free (866) 583-2392 or online at: www.mofirststeps.com

Who is Eligible for First Steps?

Infants and toddlers who have one of the following criteria may be eligible for First Steps:

Newborn Condition	Diagnosed Conditions	Developmental Delay
<p>Referred prior to 12 months of age with a birth weight less than 1,500 grams, with one or more of the following conditions diagnosed at birth or within 30 days post birth:</p> <ul style="list-style-type: none"> • APGAR of 6 or less at 5 minutes • Intraventricular hemorrhage (IVH) (Grade II, III, or IV) • Any Positive Pressure Ventilation greater than 48 hours, including ventilator or oscillator • Resuscitation/code-event requiring chest compressions 	<p>Referred prior to 36 months of age with a diagnosed condition including, but not limited to, the following:</p> <ul style="list-style-type: none"> • Autism Spectrum Disorders • Chromosomal Trisomy • Craniofacial Anomalies • Disorders of the Nervous System • Disorders Related to Exposure to Toxic Substances • Infections/Viruses/Bacteria • Other Chromosomal Abnormalities • Other Genetic/Congenital/Metabolic Conditions • Sensory Impairments • Severe Attachment Disorders 	<p>Referred prior to 36 months of age, with a half-age developmental delay, as measured by appropriate diagnostic measures, in one or more of the following areas:</p> <ul style="list-style-type: none"> • Cognitive development • Communication development • Adaptive development • Physical development, including vision and hearing • Social or emotional development

Eligibility* is determined through an initial evaluation of the child, which includes the service coordinator reviewing information about the child's birth and medical history, collecting the child's developmental history in multiple areas or an evaluator administering a test to determine the child's current abilities. The initial evaluation also includes the service coordinator gathering information from other sources with the parent's consent, including caregivers, child care providers, educators or other family members.

*Eligibility criteria for First Steps, including examples of diagnosed conditions, is available at:

<http://dese.mo.gov/se/fs/>

Grant

I just want to take a few moments to let you know how I feel about Grant's First Steps providers.

Amazing Amelia has been seeing Grant for over two years and I can't tell you enough how incredibly thankful I am to have had her in my life and Grant's! She is very encouraging towards Grant and when Amelia walks in his face lights up! She has helped me brainstorm ideas of how to get Grant doing something even if he doesn't like it very much.

InKredible Katie is always there for me to bounce ideas off of, to brainstorm on how to adapt something to work for Grant and even just to listen to me complain about life. She has given me so many ideas on how to help Grant accomplish a task such as learning to use his pointer finger, drinking out of a straw, when he needed food ground up she was a huge help, getting him to eat table foods, and much more!

Magnificent Mallory is a sweet and caring person! She does a wonderful job when she is here working with Grant and she works so hard and I feel bad that a lot of the time she doesn't always get to be rewarded for her efforts because Grant likes to talk when Mallory is not around. But nonetheless she has helped him (and me) in far more ways than she probably realizes!

And I could never forget Beth. Unfortunately my vocabulary does not extend past the obvious and I could never come up with a nickname for Beth, but that doesn't mean she hasn't been just as wonderful! Beth only comes once a month, but that one visit a month is always great. I always know when Beth comes over I'm going to have lots of ideas to play around with and make my Grant Man even smarter!

Each of these providers involves Grant's older brother, Matthew. He is included; never treated as though he is in the way. Obviously I'm pretty fond of all the women in Grant's life. He's one pretty lucky little man!

By Beth of Grain Valley, MO



Who Referred Families to First Steps?

First Steps receives referrals from parents as well as many community programs such as hospitals, physicians, child care centers, preschools and other public agencies.

Referral Sources in 2012-13	% of Active Children
Parents	45.8%
Medical Providers (Hospitals, Physicians, Other health care, Public health)	39.1%
Early Childhood Programs (Parents as Teachers, Early Head Start, school districts, child care programs, etc.)	10.8%
Social Service Agencies (Mental Health, Health & Senior Services, Shelters)	3.8%
CAPTA (Child Abuse Prevention and Treatment Act)	0.5%
TOTAL	100%

When Parents Made the Referral, How Did They Learn About First Steps?

In 2012-13 Parents Learned of First Steps From:	% of Parent Referrals
Medical Providers (Hospitals, Physicians, Other health care, Public health)	41.2%
Other Sources	38.4%
Early Childhood Programs (Parents as Teachers, Early Head Start, school districts, child care programs, etc.)	18.6%
Social Service Agencies (Mental Health and Health & Senior Services)	1.8%
TOTAL	100%

Chase

Chase was born 16 weeks early, weighing 1lb 6 oz. He spent 126 days in the NICU. He spent 7 weeks on a ventilator, suffered a stage 3 brain bleed, infections, blood and platelet transfusions and surgeries. After 10 weeks in the NICU he could not safely take a bottle and had a G-tube put in. Chase came home after more than 4 months in the hospital. A day met with both excitement and mixed blessings. He came home on oxygen, an apnea monitor and a feeding tube. He would continue to seek follow ups with several medical specialists and his pediatrician who continued to monitor his progress.

Our service coordinator, Wendy, met with us days after being home from the hospital and quickly assessed Chase's needs. Our IFSP team determined speech and occupational therapy were necessary and we got to know our providers, Erin and Alicia. It's nerve racking to care for a child with special needs, but to have to welcome strangers into your home after a journey like ours was unsettling as well. Those nerves did not take long to diminish. These ladies did a tremendous job working with Chase. They gave us a lot of ideas of activities to do at home between visits, and were very encouraging and supportive the entire time. Within 2 short months Chase no longer needed his feeding tube.

Our IFSP team later determined physical therapy was needed; Heather joined our team and she met with Chase once a month. All the while, Wendy checked in with us periodically to make sure we were being taken care of and that we were happy with services. When Chase needed speech services, Shannon joined the team. She, along with Alicia, worked on increasing Chase's attention span and focus on tasks. Today, Chase is a thriving, on-the-go 4 year old. He attends daycare 5 days a week and is in the 4 year old classroom at his center. He loves playing with his older brother, as well as trucks, cars, and anything that goes. He is certainly "all boy."

Before Chase's birth, we honestly knew very little about the program. I can't say enough about how much this program has helped our little miracle. We have a connection with each of Chase's therapists and service coordinator, and consider them part of our family. We are blessed by their dedication to their job and the families they care for. Without the services of First Steps, Chase would not be where he is today. This is a necessary program to ensure the continuation of the quality of life for little ones born prematurely like Chase.

By Julie of Pacific, MO



What Do First Steps Services Look Like?

At referral, the **System Point of Entry (SPOE)** assigns a **service coordinator** to the family. This person explains the First Steps program and guides the family through the process. The service coordinator learns about the family, including their daily activities, hopes and priorities for their child. The service coordinator also schedules and leads Individualized Family Service Plan (IFSP) meetings to identify the outcomes and services for the child and family.

Once an IFSP is developed, a **primary provider** visits with the family and the child regularly. These visits are often in the family's home or at other community places. At each visit, the primary provider works with the family on their concerns and questions regarding their child's development. Together they find ways to support the child in everyday activities. Other providers may visit the family with the primary provider; they are called **supporting providers**.

About every four to eight weeks, the primary provider attends an **Early Intervention Team (EIT) meeting** to strategize with the supporting providers, as well as additional providers from the team. EIT members include the service coordinator, physical therapists, occupational therapists, speech therapists, and special instructors. Together the EIT members explore the best way to assist families in reaching the outcomes in their IFSP.

By Nancy,

Speech-Language Pathologist

"I've been very excited to be a part of the early intervention teams through First Steps. Families really appreciate knowing that all team members are communicating and that they and their child are receiving the best services possible. As a member of the team, I like being able to talk with other providers on a regular basis and sharing ideas."

By Anne, Occupational Therapist

"In this model, families take a more active role. The primary provider can really assess the child's and family's strengths, abilities, and special needs, in the context of the family, and support the family in whatever way needed. The model gives families more time to actually incorporate suggestions, ideas, strategies into their routines and lifestyles. The support structure is fluid – which is nice and realistic. It does take teamwork, communication, role release ... to make this model successful."

By Deb, Physical Therapist

"As therapists we have always worked at providing a comprehensive and collaborative approach to all children in First Steps. The Early Intervention Team model simplifies this effort. Previously we had to find time to make phone calls or email with the other providers on the team to discuss their approaches and how things were going with their therapy. Now we are able to meet together with the family and make it a first-hand team approach."

By Angie, Occupational Therapist

"I have found that when providers make it a priority to attend monthly meetings, each provider has an opportunity to inform other members of specific strategies, brainstorm for new ideas, and solve more complex problems. Often I have questions to what another provider may see during their treatment sessions that may assist me in developing a better approach with the child and family. This is essential also to discuss how the child and family are progressing with their goals and what changes need to be made to achieve their goals."

By an Early Intervention Team in Southeast Missouri

"We make sure that our EIT meetings are held on a regular basis and we always try to attend. We work hard to communicate well with one another, not only around the meeting table, but in our home visiting as well. We respect everyone's input when we brainstorm and we make a point to celebrate our successes along the way. As a team we celebrate the progress children make. We support one another by speaking positively about our team and the teaming process to families and others in our community. We also ensure our continued success by acknowledging that every family and child is different; and as a team, we do what we need to accommodate that."

Brooklynn

Since our daughter Brooklynn was a few months old, there was concern about her large head size, which required many referrals to specialists. At our 2 year check-up, she started to fall behind in her milestones, mostly speech. We couldn't understand what she was trying to say and she started to become aggressive by biting. I was informed about the amazing program called First Steps. My pediatrician made the referral, and within a month, an evaluation was completed. We began weekly speech therapy sessions in our home with our speech therapist Tina. We soon discovered that Brooklynn had mild hypotonia, sensory issues and rigidity in play skills. This is when our special instructor, Shannon, got involved.

These 2 amazing women helped to make so many changes in our lives. They taught us skills to help Brooklynn's speech, strength and play skills. We learned to give her choices, to word our phrases so she copied us, and invite ourselves into her world slowly during play. They even taught her older sister Isabella ways to interact, which made her feel like she was an active participant. We were amazed at the progress our daughter made in the short time in First Steps. By her third birthday, she was using sentences, able to express her needs, her core strength improved, and her ability to do fine motor tasks such as picking up small objects, greatly improved. Her agility improved along with her strength. Before therapy, Brooklynn fell a lot, and she didn't have the strength to catch herself, so she hit her head many times. Now she is able to catch herself when she falls and has better balance and coordination.

In November 2012, we received a diagnosis of PTEN Hamartoma Tumor Syndrome, which explained many of Brooklynn's issues, including her speech delay and hypotonia. Tina and Shannon helped us through this diagnosis, and gave us tools to make sure we provided our daughter with the best support and best possible chance to catch up to her peers, or at least not fall further behind. They also helped us get a referral to the Early Childhood Center at our school district, where she now gets special education. They gave us an amazing start. As a full-time working mom, the convenience of coming to our house was undeniable. Your program gave my daughter the tools to interact with not only us, but other adults and peers. We will never forget all the First Steps program provided us.

By Beckie of Kansas City, MO



When the Time Comes to Leave First Steps

Before First Steps ends at age three, service coordinators and service providers help families identify community resources so that parents can continue to meet the needs of their children. This process is referred to as Transition from First Steps.

Children leave First Steps every day, moving into Early Childhood Special Education (ECSE) through the local school district or other community programs. In the past year, children left First Steps for the following reasons:

Reason for Leaving First Steps in 2012-13	# of Children	% of Exiting Children
Child turned three years old:		
Parent requested referral to ECSE - Eligible	2,437	58.9%
Parent requested referral to ECSE - Not Eligible	436	10.5%
Parent did not request referral to ECSE	223	5.4%
Family withdrew from First Steps	440	10.6%
Moved out of state	224	5.4%
Child completed IFSP outcomes	162	3.9%
Unable to contact the family	189	4.6%
Child passed away	28	0.7%
TOTAL	4,139	100%

Parents: Are You Interested in Sharing Your First Steps Story?

First Steps wants to hear from parents! Parent participation, feedback, and sharing ideas is important to making sure the First Steps program is making a difference for children and families in Missouri. Here are some ways to get involved:

First Steps SPOE

The First Steps System Point of Entry (SPOE) office is the first point of contact when families have questions, concerns, or want to share their story. The local SPOE can also assist families with finding additional community programs.

MPACT

The Missouri Parents Act (MPACT) is a statewide parent training and information center helping parents of children with disabilities. MPACT collects stories submitted by parents and provides up-to-date information, including parent resources, First Steps fact sheets, and training sessions throughout the state.

Newsletters

Families participating in First Steps receive a quarterly parent newsletter filled with program information, fun activities, helpful ideas, and parent stories.

Regional Meetings

Regional Interagency Coordinating Councils (RICCs) have been organized throughout the state to assist the SPOE with the evaluation of the effectiveness of the First Steps program within the region. RICC membership includes family members of children with disabilities, service providers, community partners, and representatives of programs serving children and families.

State Meetings

State Interagency Coordinating Council (SICC) is a group which meets quarterly. The role of the SICC is to advise and assist the First Steps program with state and federal requirements. Each SICC meeting includes a Mission Moment which allows a First Steps family to share their experience.



Grant and his family

If First Steps parents want to share their story or learn more about getting involved, please:

- * Contact your local SPOE office at: (866) 583-2392
- * Email the First Steps program at: sefirststeps@dese.mo.gov
- * Visit the MPACT website at: <http://www.ptimpact.org/>
- * Visit the First Steps website at: <http://dese.mo.gov/se/fs/>
- * Visit the RICC website at:
<http://dese.mo.gov/se/sicc/RICCContactInformation.html>
- * Visit the SICC website at:
<http://dese.mo.gov/se/sicc/>

Closing the Gap...

In 2007 a study* based on census population and prevalence measures was conducted to determine the potential number of children eligible for First Steps services in Missouri. The study identified a “gap” of 0.89%, or approximately 2,053 children who were potentially eligible for, but not served by, First Steps at the time.

Since the initial report, the System Point of Entry (SPOE) offices increased efforts to reach out to various referral sources and educate the public about the First Steps program, in an attempt to find all children potentially eligible for First Steps. The number of children eligible and participating in the First Steps program has grown tremendously in the years since the study was conducted in 2007. Based on the increase in child count, a follow-up study* was conducted in 2012.

The follow-up study found outreach activities were successful; First Steps had reduced the gap. Based on updated census populations and prevalence measure, the gap reduced to .30%, or approximately 690 children. This gap may not be completely closed because First Steps is a voluntary program and families of eligible children do not have to participate. However, the SPOE offices continue to reach out to referral sources in an attempt to increase the number of children participating in the First Steps program.

* To review the 2007 and 2012 studies on First Steps Eligibility Review and Forecasting, visit the Missouri Research and Demonstration Projects website at:

<http://dese.mo.gov/se/fs/ProviderResourcepg.html#Missouri>

First Steps Child Count and Cost

	FY09	FY10	FY11	FY12	FY13
December 1 Child Count *	3,784	4,200	4,539	5,024	4,999
December 1 Child Count Yearly % Increase	10%	11%	8%	11%	-0.5%
Total Children Served in FY **	8,352	9,183	9,864	10,659	11,194
Total Cost per Child ***	\$3,925	\$4,008	\$4,057	\$3,770	\$3,374
Direct Service Cost per Child ****	\$2,724	\$2,809	\$2,886	\$2,670	\$2,380

* Total number of children with an active IFSP on December 1

** Total number of children who had some type of First Steps service (evaluation, IFSP meeting, or direct service)

*** Total cost per child including administrative, training, testing and direct service costs

**** Direct service cost per child including evaluation, IFSP meeting, direct service and mileage



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